



The development and validation of the Leiden Burdens and Needs Questionnaire for patients with a Pituitary disease: the LBNQ-Pituitary

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Introduction

The increasing number of QoL studies in patients with pituitary diseases suggest a growing interest in the patient's perspective on QoL and patient reported outcome (PRO). However, until now no measure is available assessing the patient perceived burden of these impairments and their needs for help for these issues.

Objective

To develop and validate a disease-specific burdens and needs questionnaire for patients with a pituitary disease.

Methods

Patients: A total of 337 patients with pituitary diseases completed the questionnaires (response rate 63%).

Development questionnaire: Items for the Leiden Burdens and Needs Questionnaire for patients with pituitary diseases (LBNQ-Pituitary) were formulated based on results of a recent focus group study¹. Each item on the LBNQ-Pituitary consisted of three parts (figure 1):

- Whether a certain complaint was present (*Yes/Somewhat/No*);
- The extent to which the patient is bothered (*burdens*) by the complaint which was scored on a 5-point Likert scale (0=*not at all* - 4=*extremely*);
- The extent of importance that patients placed on the attention they received from their healthcare provider for their complaint (*needs for help*), scored on a 5-point Likert scale (0=*not important* - 4=*extremely important*).

For each item the burden and needs for help were separately scored.

Validation: Construct validity of the LBNQ-P was examined by using an exploratory factor analysis on the burden part of all items. Reliabilities of the subscales were calculated with Cronbach's α , and concurrent validity was measured assessed by calculating Spearman correlations between the dimensions of the LBNQ-Pituitary and the other questionnaires (EuroQoL-5D, SF-36, MFI-20, HADS, UCL, GSE, IPA).

Conclusions and future directions

The LBNQ-Pituitary is a valid and reliable instrument to measure pituitary-related burden and potential unmet needs. Future research is needed to further establish the psychometric properties, for instance by using a confirmatory factor analysis in another cohort of patients with a pituitary disease.

We postulate that the LBNQ-Pituitary can be used in clinical research (e.g. comparing burden and needs between groups, evaluate the effect of interventions). It can also be used to facilitate the assessment of potential unmet needs in clinical practice (LBNQ-Pituitary Needs Index, Figure 2), but further work is needed to evaluate this.

1. As a consequence of my pituitary condition, I experience **fatigue**.

a. YES / SOMEWHAT / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

Not at all Slightly Moderately Considerably Extremely

c. I find attention for this problem from my health care providers to be

Not important Slightly important Moderately important Considerably important Extremely important

Figure 1. Item of the LBNQ-Pituitary

Results

Construct validity

The exploratory factor analysis produced seven subscales in the LBNQ-P (33 items): Mood, Cognitive functioning, Illness perceptions, Sexual functioning, Social functioning, Anxiety, physical complaints.

The sum scores of the subscales were all transformed to a 0-100 scale.

Reliabilities of subscales

All subscales were found to be reliable (Cronbach's alpha .736, or higher).

Concurrent validity

Strong and consistent correlations were observed between the subscales of the LBNQ-Pituitary and outcomes on the other questionnaires.

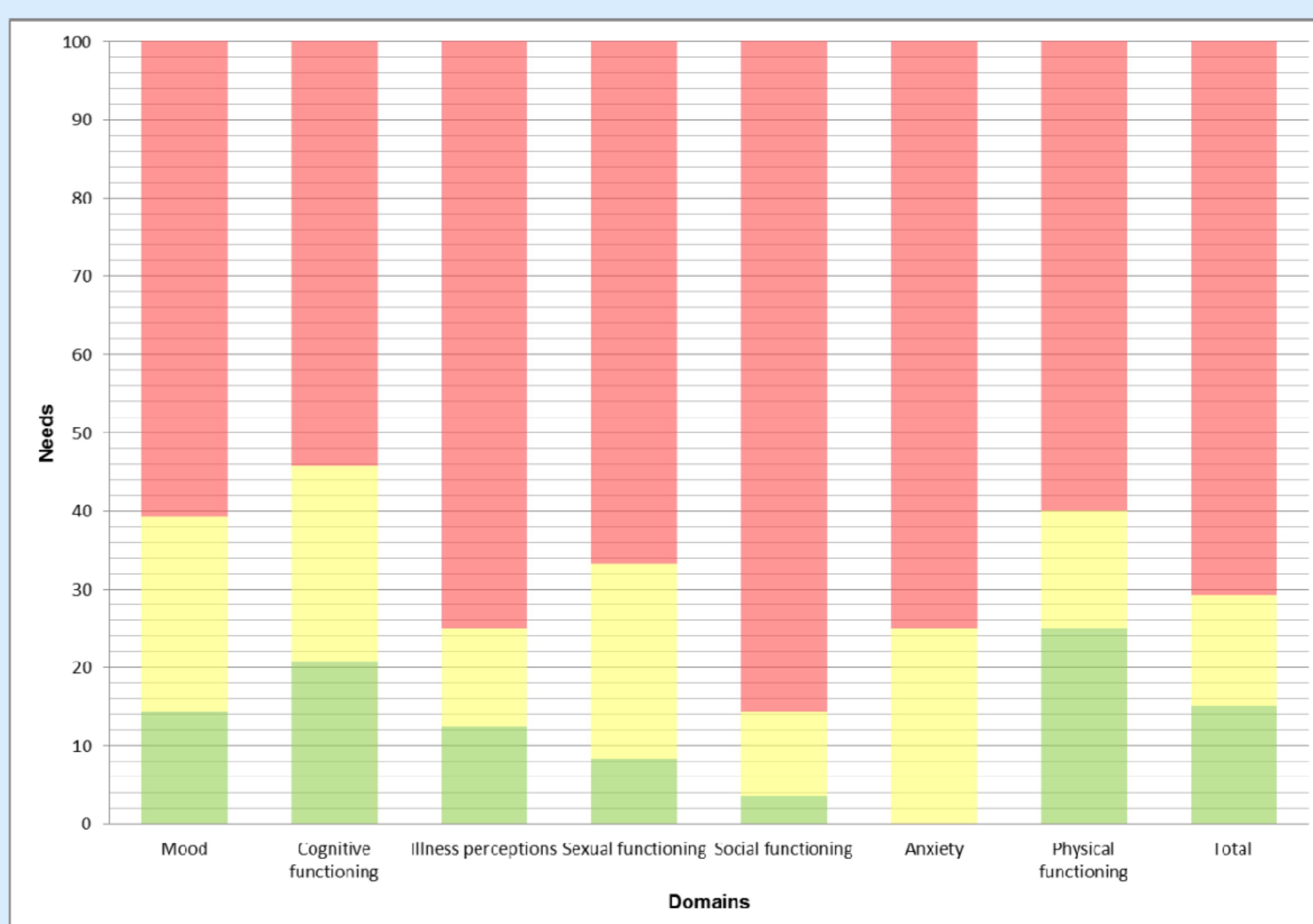


Figure 2. LBNQ-Pituitary Needs Index

Green: lowest needs reported by 60% of the patients; **Yellow:** medium needs reported by 20% of the patients; **Red:** highest needs reported 20% of the patients

References

- Andela et al., Pituitary 2014; 18(1):86-100.



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